

## COMMENTARY

## Policies, procedures, and the irony of protections

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**Competing interests:**  
None declared

*West J Med* 2002;176:22

To have severe developmental disabilities and to be nearing the end of life is to be rendered twice vulnerable. Aspects of the dying process deemed important by patients confronting terminal illness—physical comfort, respect for personal preferences and autonomous decisions, a sense of spiritual completion, affirmation of the whole person, and connection to others—are aspects of living most threatened for profoundly disabled people. How, then, can the end-of-life experience be made as humane and dignified as possible when the life that preceded struggled with just this problem?

On these pages, we read about how one long-term care center for people with developmental disabilities has addressed this challenge. Here, only one in five of the residents at the facility have family still involved in their lives. If these relatives or an employee raises concerns about the proper course of medical care when a resident takes ill, a diversely-composed bioethics committee labors to determine what would be in the resident's best interest and then pilots the appropriate therapeutic course, ranging from full treatment to withholding resuscitation or hospitalization.

The result? Only a quarter of the resident deaths occurred after the committee had contemplated what would

be the best form of end-of-life care. And among those residents for whom the committee did decide to limit care, more than half had died within a week.

This report reinforces a lesson that only grows clearer as time passes: Excellent end-of-life care simply cannot be squeezed into the very end of life. Too many opportunities for good palliative work are lost by failing to reevaluate the underlying objectives of medical care. We must learn to manage our mortality better, not simply regarding planning for an end to life, but how to weave the fundamental goals of that plan throughout each and every day.

A second lesson is also evident: Policies and procedures, even when designed and enacted with best intentions, can have ironic consequences. In this instance, those most in need of protection—bereft of family—were least likely to have a bioethical care conference initiated on their behalf. Similar observations can be made in end-of-life care generally, where the existence of advanced-planning documents matters little compared with the effect of having a dedicated advocate, where the disenfranchised often have neither, and where all of us will at some point conceivably need to be protected against the best that technology has to offer.

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